

The Personhood Kit

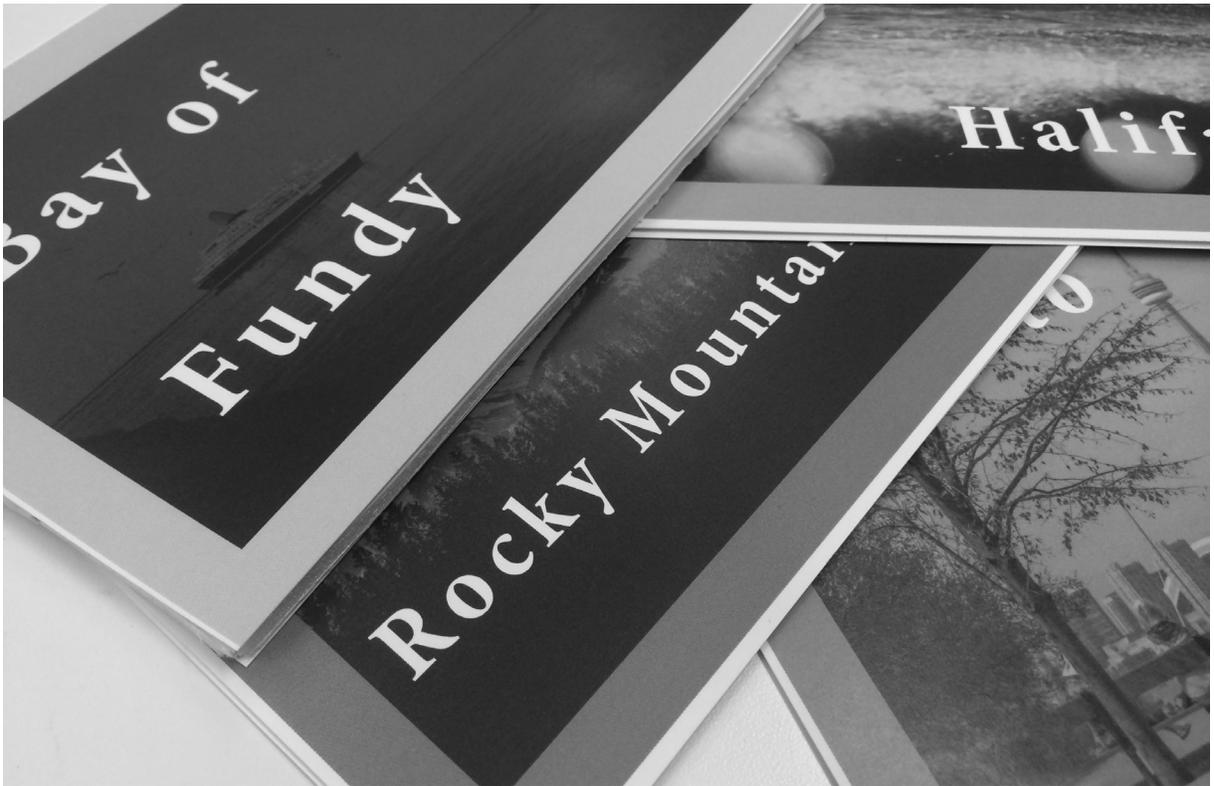
Project

Facilitating Personhood for Residents with Advanced Dementia

Living in Long Term Care

November 2019





Executive Summary

The personhood kit project was launched to assist in supporting personhood for the residents of Cedar House. Personhood is the qualities that make up an individual, it is how we express who we are. In the face of cognitive diseases, like dementia, an individual's ability to advocate on behalf on their own personhood can dramatically decrease. The intent of the Personhood Kit Project, was to explore how the introduction of specially designed kits containing materials related to various life experiences may support personhood for individuals with advanced stages of dementia. The project was trialed on Cedar House, a 25-bed secured dementia house for individuals in advanced stages of dementia, at Loch Lomond Villa. Each resident received an individually tailored personhood kit related to significant moments from their life history.

Cedar House was selected as the residents of this house, often rely on staff, family, and volunteers to support their personhood. It was theorized that in bringing in a supportive material would allow residents, and other actors on the house to learn and explore the diverse life experiences and identities of the residents of Cedar House.

The Personhood Kit project was supported from funding from CABHI Spark Program, New Brunswick health Research Foundation, and Loch Lomond Villa. The project was developed over 14 months from September 2018- October 2019.

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Conclusion

An elderly couple is walking away from the camera on a gravel garden path. The man is on the left, wearing a light green shirt and khaki pants. The woman is on the right, wearing a light-colored jacket and a blue skirt, and is using a walking stick. The path is surrounded by lush green foliage and trees, with a brick pillar visible on the right side. The scene is brightly lit, suggesting a sunny day.

Introduction

Introduction

The discourse on dementia research infers that dementia will result in the eventual erosion of individual self-hood, agency, and citizenship (Kontos, Miller, & Kontos, 2017). This loss of self suggests that persons with dementia will decline to a state of un-being, in which no person exists (Kitwood & Benson, 1995). However, emerging research suggests that the behaviors of persons with dementia are not entirely controlled by cognition (Dupuis, et al., 2012). Personal histories, social contexts, and social interactions also hold a strong influence on how persons with dementia behave and operate within care environments (O'Connor, et al., 2007). Person centered care has emerged as an ideology to support personhood for persons with dementia.

It enables individuals with dementia to exercise choice in their care, express their feelings, and develop meaningful relationships with staff, other residents, and visitors (Kontos, 2005). The shift to person-centered care, further supports how individual personhood should be acknowledged within the clinical environment. The emergence of person-centered-care has heavily influenced long term care. Person-centered-care has become the new standard of care within the North American healthcare environment (SOURCE). This new standard also offers more opporthouseies to support personhood for care recipients. Personhood is the qualities that make up or define an individual, these qualities are one way we can understand ourselves as an individual or a person (Dewing, 2008).



Within healthcare environments, personhood is a philosophy that challenges stigma associated with illness and asks us to have awareness in how we interact with others. Kitwood (1997), argues that within Western societies, personhood has been reduced to two categories: individual rationality and autonomy. Higgs & Gilleard (2016), suggest that this implies that persons within this group lack the basic “cognitive infrastructure” (pp.773) to fit within what we consider to be a person. Personhood is important in care as people with dementia may experience a decline in their cognition and may be reliant on healthcare staff to meet these needs (Mitchell & Agnelli, 2015).

To support personhood on Cedar House this project had 2 primary goals

01 Create an opporthousey for residents to connect and explore key experiences that defined and shaped identity. Use the kits as a catalyst for residents to reconnect with their sense of self, and explore and recognize their sense of self outside of the care space.

02 Offer staff, family, and volunteers an opening to learn more deeply about the residents they see everyday. We aimed to create an opporthousey to learn about who the residents are, and how to use the information to connect with them in new ways.

... used to comply with 2.13.3.4.5(a), (b) where applicable, (d), or (e), or 2.13.3.4.7(d), (e), (f), or the device is capable of sensing the defined the appropriate signal is sent to the operation control (see 1.3). If the device is incapable of sensing the object or sending the appropriate signal, power closing of the door(s) or gates(s) shall be rendered inoperative.

2.13.3.4.10 When building conditions would render ineffective or nonoperational the detection means required by 2.13.3.4.5(a), (b), or (c), 2.13.3.4.6(c), (d), or (e), or 2.13.3.4.7(d), (e), (f), or (g), the following shall be provided in lieu of compliance with 2.13.3.4.5(a), (b), or (c), 2.13.3.4.6(c), (d), or (e), or 2.13.3.4.7(d), (e), (f), or (g):
(a) continuous-pressure closing of the car door or gate and hoistway door in compliance with 2.13.3.4.1
(b) usage shall be limited to authorized personnel only. A sign in compliance with 2.16.5.2 shall be provided but shall read: "THIS IS A FREIGHT ELEVATOR, NOT A PASSENGER ELEVATOR, AND NOT FOR PUBLIC USE. NO PERSONS OTHER THAN AUTHORIZED PERSONNEL ARE PERMITTED TO OPERATE THIS ELEVATOR."
(c) sequence operation in compliance with 2.13.6.1
(d) the average closing speed of the car door or gate shall be limited to 0.20 m/s (0.67 ft/s)

(b) Where a reopening device configuration is used, the closing door system shall follow the following requirements:
(1) The kinetic energy computed at any point in the Code zone shall not exceed 23 J (17 ft-lbf)
(2) The kinetic energy computed as determined in 2.13.4.2.2 shall not exceed 10 J (7.37 ft-lbf)
(3) Where a reopening device is not used, the kinetic energy computed at any point in the Code zone shall not exceed 8 J (6 ft-lbf)

(1) The kinetic energy computed at any point in the Code zone shall conform to the following:
(2) The kinetic energy computed at any point in the Code zone shall not exceed 8 J (6 ft-lbf) or in any exposed opening shall conform to the following:
(1) The kinetic energy computed at any point in the Code zone shall not exceed 8 J (6 ft-lbf)
(2) The kinetic energy computed at any point in the Code zone shall not exceed 8 J (6 ft-lbf)

2.13.4.2.2 Door Travel in the Code Zone

(a) For all side sliding doors and hoistway doors, the Code zone distance from the open jamb to a point in the Code zone shall not exceed 2.13.4.2.2.2

(b) For all side sliding doors and hoistway doors, the Code zone distance from the open jamb to a point in the Code zone shall not exceed 2.13.4.2.2.2

2.13.4.2.3 Door Force

The force required to operate the hoistway door or gate if power operated) from the leading edge of the door shall not exceed 30 lbf (see 2.13.3.1). This force shall be measured between one-third and two-thirds of the door height.

2.13.4.2.4 Data Plate

2.16.3.3 shall be attached to the car crosshead and shall contain the following information:
(a) minimum door closing speed
(b) minimum door opening speed

(a) minimum door closing speed as specified in 2.13.4.2.1(f)
(b) minimum door opening speed as specified in 2.13.4.2.2

Research

Research

To explore the experiences of persons with dementia the research collection process was concentrated to Cedar House, a secured dementia house of a long-term care facility at Loch Lomond Villa. Cedar House has 25 residents that range between moderate to advanced stages of dementia. Residents of Cedar House are unable to leave the house independently and require the assistance of staff, volunteers, or care partners to leave. Many interventions currently exist on Cedar House to support personhood. For example, tools like life like baby dolls, fiddle boxes with various textual materials, shadow boxes, fiddle boards, and a snoezlen room are all available to use with residents to support personhood. However, few interventions existed on the house to support meaningful and individualized personhood opportunities based on residents own personal experience. Investigations on how to improve personhood for persons with advanced dementia were informed through the following methodologies: a scoping literature review, semi-structured interviews and co-design.

These methods permitted an understanding of the needs of dementia residents and other actors in the care space, the challenges of preserving personhood in the care space, and how information about residents' life history was shared amongst the actors. Daily variances in cognitive functioning among residents with dementia prohibited the direct participation of this population in the data collection process. To provide consent the participant must have the capacity to ask questions about the risk or process of the research, residents with advanced dementia are unable to do so (Hedge & Ellajosyula, 2016). In respecting this level of decision-making capacity, the residents of the house were excluded from the research process. To inform this point of view, data was collected from proxy participants (care staff, volunteers, and care partners) who spend large amounts of time interact with the residents that were able to inform the development of the design intervention.

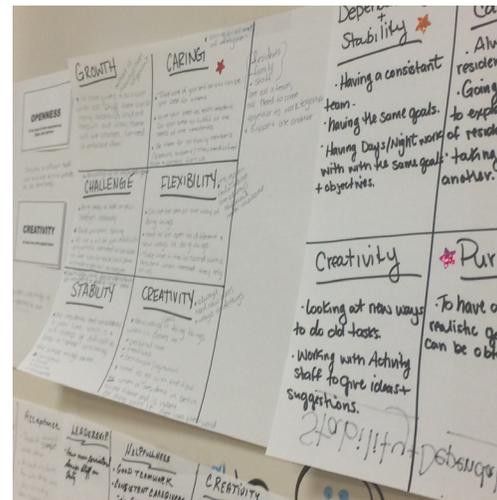
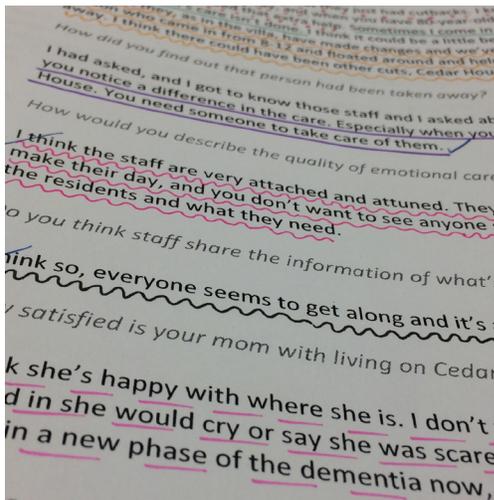
Research Methods

01 Co-Design

To better understand the values and beliefs actors in the care space held, 1 co-design session was held. The co-design session had 7 participants separate from the interview process. The co-design session was developed to work with key stakeholders to understand how a design could be implemented that would be both meaningful to the residents while also respecting the role of these stakeholders in its execution. Two activities were conducted. First, participants were asked to rank the values, using pre-made value cards, of the house as they perceived them to be now. Second, they were asked to rank them based on what they wanted the main values to be on the in an ideal setting. Participants then worked as a group to storyboard what the ideal dementia house would look like, and how it was encompassing of resident personhood.

02 Interviews

To explore the complexity of preserving personhood in advanced dementia semi-structured interviews were conducted over different phases of the project. Interviews were first held to examine how information about resident's life histories or personhood, was shared in the care space and how it was used in care practice on the house. Two more rounds of interviews were conducted to examine how the personhood kits were received by care staff, care partners, and volunteers on the house.



Left: Coding of interviews Right: image from co-design exercise.

“Personhood is a standing or status that is bestowed upon one human being by others in the context of relationships and social being. It implies recognition, respect, and trust.”

Thomas Kitwood (1997)

The outcome of the research process first, was the development of a framework, design principles that addressed the primary needs of Cedar House, and the integration of an established framework of categories of identity developed by Cohen-Mansfield, Dakheel- Ali, & Marx (2009). The combination of both primary and secondary research evidence compiled in this research process ensured that the data collected was triangulated. Many points of view were captured in this process and created an understanding of the many dimensions of personhood in advanced dementia.

Research Outcomes

The framework was developed through the analysis of the information collected in the research phase of the project. The outcome was 4 core themes. These themes informed what the personhood kit project needed to address in its launch. In understanding this information, we were able to curate the kits to meet the needs and values of the residents, staff, family, and volunteers of Cedar House. The themes are as follows.



Attachment

Actors feel motivated to be in the care space because of their relationship with the residents. The current structure of the environment is disorganized and offers little support that creates burnout for staff and negatively influences how personhood is sustained.



Purposefulness

The care space does not offer goals/objectives/functions for the residents that support their personhood or provide opportunities for consistent meaningful engagement. This lack of purpose does not acknowledge the unique experiences of the residents and may facilitate impulsive behaviors.

Research Outcomes



Information Availability

Information about resident personhood and daily changes is restrictive to care staff. This does not acknowledge/value the many relationships in the care space that may further support resident personhood.



Support

Family members and staff develop deep and meaningful connections to the residents of Cedar House. These relationships create a desire amongst these groups to improve the resident experience through advocacy and future ideas to improve the care space.

Research Outcomes

In addition to the analysis, a review of published literature on personhood was reviewed. To strengthen the personhood kits, the information learned from this review was also incorporated in the Personhood Kit Project. One framework exploring potential domains of identity, was used to structure the materials placed in each personhood kit. Identity is ever evolving and is multidimensional, but can be broken into 4 components or domains that are common across the human experience (Cohen-Mansfield, Dakheel-Ali, & Marx, 2009). These components are (1) work, (2) hobbies, (3) attributes, and (4) family. When these domains are used in the care of a person with dementia this may improve their interest in activities, pleasure, reduce agitated behaviors, and improve orientation in the care space (Cohen-Mansfield, Dakheel-Ali, & Marx, 2009). This conceptualization of identity was used in the development of the Personhood kits.

Values and principles were also developed after key values emerged from the research process. Each value was then worked into a principle statement. These statements were used as guidelines during the development of the Personhood Kit. Three primary values were identified. They are as follows:

1. Dignity

The kits should respect and recognize the diverse & wide-ranging life experiences of the residents of Cedar House.

2. Self-worth

The kits should facilitate moments that promote individual happiness and respect residents.

3. Relationships

The kits should acknowledge the many stakeholders who interact with residents and further support their personhood.

Research Outcomes

Interviews were also conducted after the launch of the personhood kits to examine how the kits were received from stakeholders in the care space. Information from this interview round revealed that further information about how to access the kits was needed to support the project. To acknowledge this feedback and better disseminate the personhood kit project, information cards were created. The cards had information on both the front and back sides. The front of the information card reiterated that the project was launched and all kits were on the house. The back of the information cards showed a small storyboard. The storyboard, used images of the space, and highlighted how to unlock the cabinet where the kits are located, and where to access the key.

The final interviews revealed that these changes to information sharing were successful and participants found the cards helpful.

Participants appreciated being able to access keys to use the personhood kit without having to rely on nursing staff to open the cabinet.

The Personhood Kit Project

Did you know the personhood kit project is complete? Each Cedar House resident has a special box with materials related to meaningful moments they've experienced over their lifetime.

You will need a key to access the kits, they are behind the Key painting on the wall of the activity room. Open the painting to get the keys.

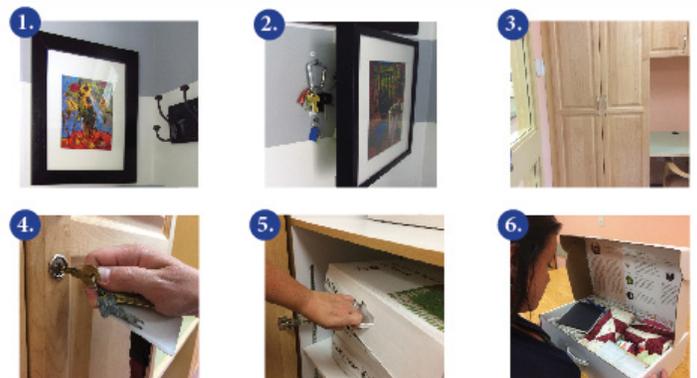
Family members are welcome to use the kits while visiting. They are located in the activity room, to the left of the kitchen.



Above: front side of information card.

Below: Back side of information card.

How to Access the Kits



cky Mountains

Design

Bay of Fundy

I have made from the
best of the water
and you see
I am

Sf

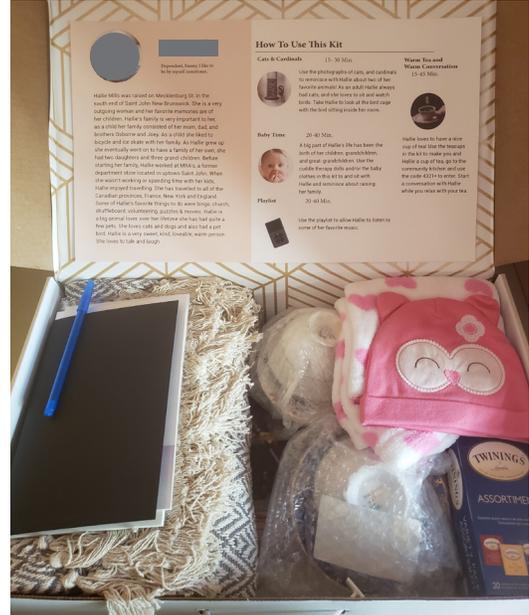
Design

The personhood kits were designed to make personalized reminiscences experiences for each resident. Upon opening the kit, the user is greeted with the lid that contains a narrative on each resident, a photo of each resident, descriptions of their typical behaviors, and instructions on how users could use the materials in the kit were listed inside. These choices were made to support users of the personhood kits, and create an experience that was intuitive and straightforward. The research team hypothesized that in developing a design with this in mind, this would increase the usability of the personhood kits on Cedar House. All of the materials created for the Personhood kits have been developed in acknowledgment of the identity framework developed by Cohen-Mansfield, Dakheel-Ali, & Marx (2009). In doing so, this may support sense of self for persons with dementia.

It is hypothesized that when persons with advanced stages of dementia interact with the personhood kits it may support the recollection of different past personal memories, experiences, or interactions. Materials in the kits differed depending on the residents life history. Materials that may have supported personal experiences were purchased, this included items like books, painting materials, exercise equipment, jewelry, etc. Additionally items were graphically designed to support these experiences as well. These materials included letters, post cards, traditional occupation work punch cards.

The Personhood Kits

Each personhood kit was unique to individual residents on Cedar House. The kits contained different and various materials depending on the resident and their life history. Materials in the kits differed depending on the residents life history. Materials that may have supported personal experiences were purchased, this included items like books, painting materials, exercise equipment, jewelry, etc. Additionally items were graphically designed to support these experiences as well. These materials included letters, post cards, traditional occupation work punch cards. As a result, each kit represented the unique and diverse life experiences of the residents of Cedar House.



The Personhood Kits

Common design elements were placed in each kit to create an easy to use experience for a variety of actors that may use them on Cedar House. Upon opening each kit, the user is greeted with a narrative highlighting key information about a residents life history and what they've done over their life time that may have contributed to their personhood. The narrative also offers a picture of each resident, and 2 or 3 keywords that describe their typical personalities on Cedar House. This was done to allow users engaging residents with the kits, an idea of what they could potentially expect when interacting with a particular resident. To the right of the narrative the user will find instructions on how to use the materials in the kit. The instructions highlight how the items in the kit links to a significant memory for the resident, and how long the activity should last.

Object Rationale

Items within each personhood kit differed depending on the life experiences and history of each resident. However, the items that were selected for each kit were selected with regard to the identity domains defined by Cohen-Mansfield, Dakheel-Ali, & Marx, 2009. These domains are (1) work, (2) hobbies, (3) attributes, and (4) family.

Work

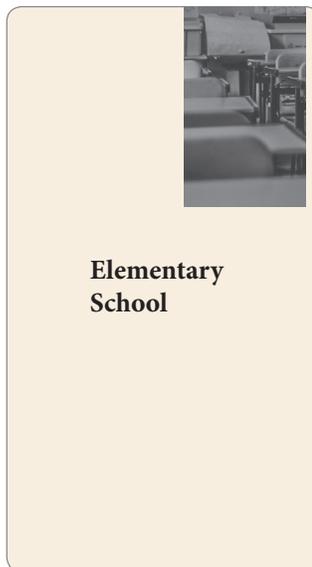
Work was represented through purchased items like books, and also graphically designed time punch cards of traditional occupations relevant to a dementia population (typist, teacher, mechanic).

The Personhood Kits

Work

Objects and audio linked to previous common occupational roles may allow for persons with dementia to reminisce about their memories, connect with others who shared similar occupations, and satisfy the need to show usefulness within the care space.

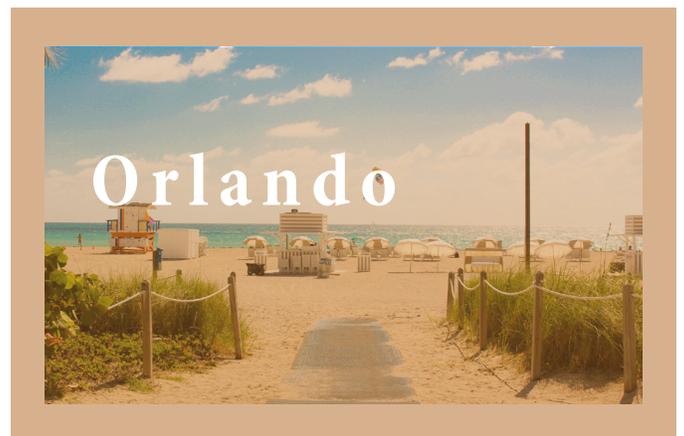
NO.		Pay Period Ending	
Name		E. McSpillan	
Extra Time		Regular Time	
1st Day	AM	7am	
	Noon	5pm	
	PM		
2nd Day	AM	7am	
	Noon	5pm	
	PM		
3rd Day	AM	7am	
	Noon	5pm	
	PM		
4th Day	AM	7am	
	Noon	5pm	
	PM		
5th Day	AM		
	Noon		
	PM		
3 hrs.			



Above: sample time punch card

Hobbies

Hobbies were represented through purchased materials like jewelry boxes, exercise equipment, painting materials. Additionally, postcards of different locations that have been visited by residents were created. Recollection of places and environmental memories can be more accessible to persons with dementia (Chaudhury, 2002). Placed-based reminiscences using colourful photographs, sketches, and sound can be used to allow persons with dementia to explore memories of past life experiences and interactions (Chaudhury, 2002).



Above: sample of front of postcard

The Personhood Kits

Attributes

Attributes were represented through letters highlighting personal achievements commonly experiences (graduations, retirement, etc.). These significant moments in individuals lives that can be associated with great personal growth and change.

Family

Family was represented by involving care partners in the construction of each personhood kit. Care partners were informed of the project and welcomed to use the kits with residents and invited to place materials in the kits that may support the family identity domain.

Playlists and Audio Narratives

In addition to the materials within each kit, a playlist was created for each resident. The playlists contained their favorite music from over their lives. Many older adults with dementia in various stages of the disease are able to engage and appreciate music despite the loss of cognition (McDermott, Orrell, & Ridder, 2013). Music may reaffirm residents personal and cultural experiences with song lyrics and can facilitate a sense of familiarity.



Above: sample of letters

The Personhood Kits

Playlists and Audio Narratives

In addition to the playlists, care partners were invited to record a memory of the resident and have it placed on the playlist. This further contributed to the family identity domain. Sound has been shown in various ways to positively affect residents with dementia living in long term care. Music played during care, meal times, in recreational programs, etc. has been proven to improve the mood and interactions persons with dementia have in care spaces, and reduce responsive behaviors in the care space (Ragneskog & Kihlgren, 1997). Sound can also stimulate our implicit memories, which are unconscious memories individuals have relating to previous experiences and memorized steps taken to complete tasks (Harrison, Son, Kim, & Whall, 2007).

Persons with dementia are able to preserve their implicit memories into late stages of their diagnosis. Harrison, et al., (2007) suggest that implicit memories can be stimulated in persons with dementia by offering meaningful engagement opportunities that are relevant to the person's life experiences. Objects related to these experiences used in tandem with sounds may be used with persons with dementia to stimulate their implicit memories and their personhood.





Scale & Legacy

Limitations

Scale & Legacy

The personhood kit project was developed to assist persons with advanced stages of dementia reconnect with key life experiences that are central to their identity and sense of self. The project was contained to Cedar House, a 25-bed secured dementia house. Procedures were developed to support the kits through the recreation team at Loch Lomond Villa after the completion of this trial. To further support this, a variety of materials were purchased to build kits for future residents of Cedar House to support their personhood. Materials were purchased using the domains of identity 1) work 2) hobbies, 3) personal achievements and 4) family from the Cohen-Mansfield, Dakheel-Ali, & Marx, (2009) framework. These materials are located on Cedar House and are intended to be used as future personhood kits develop. As well, materials in current kits that can be repurposed to be used for future Cedar House residents.

Within the new procedure for the personhood kit project, family members will be encouraged upon their care partners admittance into Cedar House to participate in building a personhood kit for their care partner. They may choose to bring in supporting materials to be placed in the kits, and the recreational therapy team may use the excess materials to create new kits. The personhood project may extend into other houses of Loch Lomond Villa. However, this would be at the discretion of the recreational therapist of each house. The kits are created for persons with advanced dementia whose ability to advocate on behalf of their own personhood has dramatically decreased.

Limitations

Limitations with the Personhood Kit project include the following:

As mentioned earlier, residents with dementia were excluded from the research process. The design is assuming that it meets the need of residents with dementia in exploring personhood, however this is not confirmed by residents directly.

The personhood kit project also does not address issues of time management on the house. During the research process many staff participants emphasized the lack of time available to use these kits during their shift. Modifications were made to how the personhood kits were introduced to the Cedar House staff, but we were unable to offer more time for staff to use the kits by bringing in additional support staff, etc. However to attempt to mitigate this, family members were offered additional education and encouraged to use the kits during their visits on the House.

While the personhood kit project was being developed, a decision was made to open another research project specific to Cedar House. The dual launch of two research projects on a small 25 person house, created confusion amongst care partners, and staff. The projects were sometimes confused with one another, despite offering separate outreach on both projects.

Finally, in addition to the launch of the kits a decision was made to create a reminiscence space where the kits were stored. Conflicts with the graphic design company tasks with creating wall decals for this space, prevented the space from being fully completed before the end of the Personhood kit project. This may have affected the final interview data collected, and participants final perceptions of the project.

Conclusion



Conclusion

Personhood is integral to the human experience. It is how we understand who we are, and it motivates us in our decision making throughout the life course. In the face of cognitive disorders like dementia, our ability to advocate on behalf of our personhood weakens, but this does not mean that our personhood ceases to exist (Kitwood, 1997). Persons with advanced stages of dementia are still able to understand their identity, but may rely on their relationships with other to provide context on who they are (Kitwood, 1997). Care staff, care partners, and volunteers can provide this context to person with dementia, but are restricted in the amount of time they can invest in these relationships. As a result, person with dementia living in long term care may exhibit disruptive and agitated behaviors towards other residents and care staff in care space (O'Connor, et al., 2007).

There is a need for interventions to support personhood for residents with dementia in long term care that do not require additional work from care staff or care partners, but can provide enriching and meaningful interactions for residents with dementia.

It is hypothesized that when residents interact with the personhood kits and the materials within the kits, will allow residents with dementia to connect with previous experiences they may have had over the course of their lives.

Providing this engagement for persons with dementia may offer this population the opportunity for consistent meaningful engagement. It can allow persons with dementia to contextualize their identity beyond the care space they currently reside within. In doing so, this may provide residents with a sense of purpose in the care space and reduce aggressive and combative behaviors.





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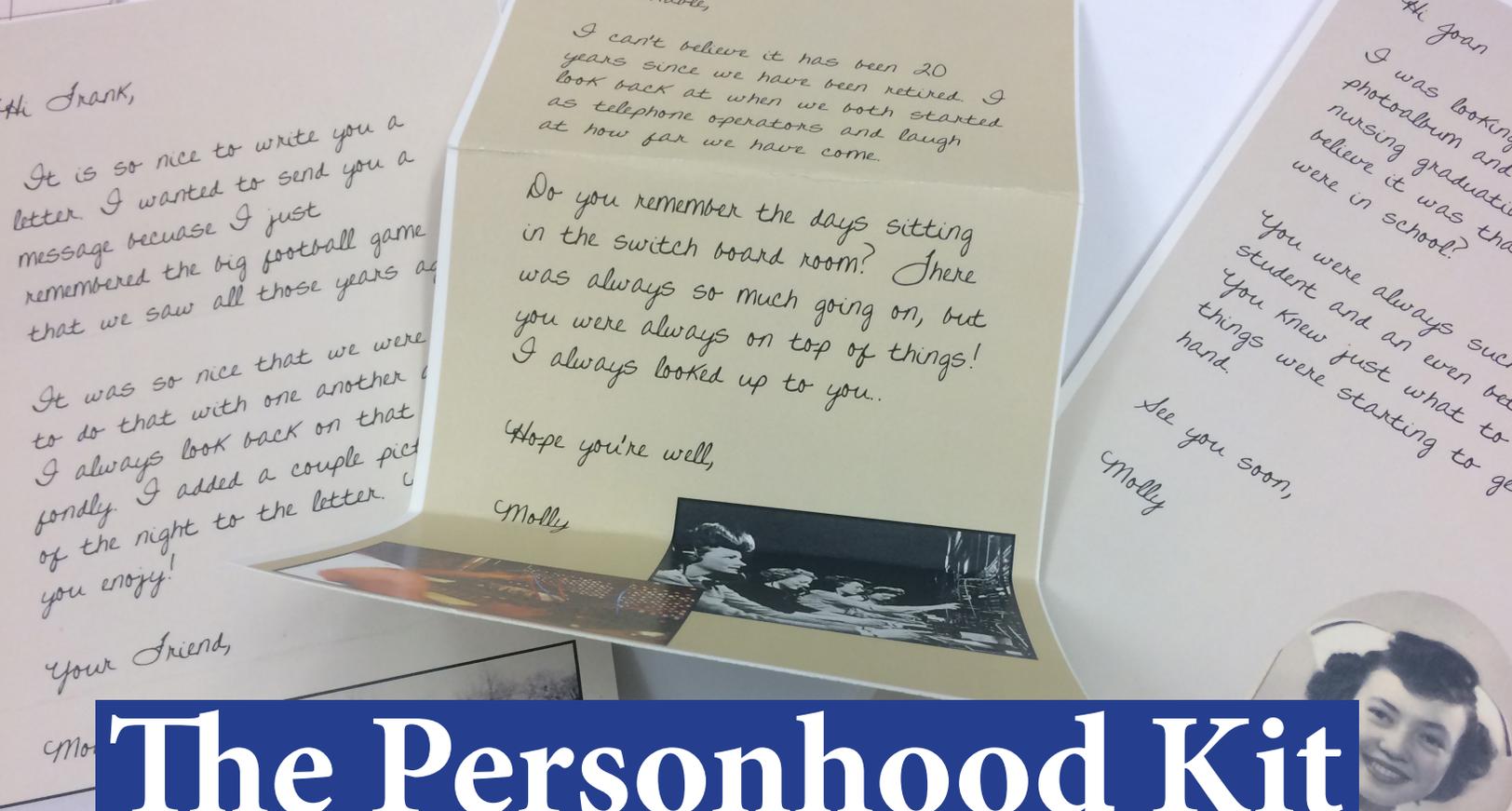
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